

Cancer control-planning and monitoring population-based systems

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Abstract

Cancer is a growing global health issue, and many countries are ill-prepared to deal with their current cancer burden let alone the increased burden looming on the horizon. Growing and aging populations are projected to result in dramatic increases in cancer cases and cancer deaths particularly in low- and middle-income countries. It is imperative that planning begin now to deal not only with those cancers already occurring but also with the larger numbers expected in the future. Unfortunately, such planning is hampered, because the magnitude of the burden of cancer in many countries is poorly understood owing to lack of surveillance and monitoring systems for cancer risk factors and for the documentation of cancer incidence, survival and mortality. Moreover, the human resources needed to fight cancer effectively are often limited or lacking. Cancer diagnosis and cancer care services are also inadequate in low- and middle-income countries. Late-stage presentation of cancers is very common in these settings resulting in less potential for cure and more need for symptom man-

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agement. Palliative care services are grossly inadequate in low- and middle-income countries, and many cancer patients die unnecessarily painful deaths. Many of the challenges faced by low- and middle-income countries have been at least partially addressed by higher income countries. Experiences from around the world are reviewed to highlight the issues and showcase some possible solutions.

1. Introduction

The trouble with the future is that it usually arrives before we are ready for it. (Arnold Glasgow)

Globally, nearly 60 million people died from all causes in 2004 with about one-eighth of these deaths (~7.6 million) resulting from cancer¹. More than 70% of the world's deaths from cancer presently occur in low- and middle-income countries where the financial, infrastructural, and human resources needed to combat the disease are severely limited. Several factors will likely contribute to even more cancer deaths in the future. The population of the world is projected to increase by approximately 80 million per year in the first half of the 21st century with a disproportionate fraction of this increase being among the elderly, in whom cancer risk is highest. The rate of increase in the number of persons over 65 years of age will increase five times faster than the total population², and given that epithelial cancer risk increases at approximately the fifth to sixth power of age³, a growing number of elderly citizens on the planet will mean an explosive growth in cancer cases and deaths, barring a dramatic change of current demographic trends and cancer risks. Unfortunately, it appears most likely that cancer risk will move in the direction of more rather than less risk, since known risk factors (e.g., tobacco use, obesity/physical activity, reproductive patterns, etc.) are trending toward causing more not fewer cancers globally.

"Cancer control" describes the totality of activities and interventions intended to reduce the burden of cancer in a population, either by reducing cancer incidence or mortality, or by alleviating the suffering of people with cancer. Generally, cancer control is seen as comprising prevention, early detection, diagnosis, and treatment including psychosocial and palliative care. At the 58th World Health Assembly (WHA) in May 2005, a resolution was approved on cancer prevention and control that called upon all 192 members of the World Health Organization (WHO) to develop national cancer control plans and programs. Well before this formal WHA resolution, the WHO had been urging countries to develop national cancer control plans. Unfortunately, such plans do not exist in most countries and even where a written plan does exist, it is often poorly resourced and therefore inadequately im-

plemented. National Cancer Control Plans (NCCPs) provide a blueprint or framework for each country to assess its cancer control needs and to develop interventions based on those needs aimed at reducing the cancer burden.

To understand the cancer burden in a given setting, surveillance is needed. It is impossible to be "evidence-based" in cancer control if little or no evidence is available. The "gold-standard" in cancer surveillance is a population-based cancer registry wherein information on new cancer cases is systematically collected on a continuing basis. The data from such a registry, together with corresponding census data, allow for the calculation of cancer incidence rates which can be compared between and among different populations and tracked over time as a measure of progress (or lack thereof) in cancer control. The International Agency for Research on Cancer (IARC), a component of the WHO, periodically collects and publishes data from the world's high quality cancer registries as *Cancer Incidence in Five Continents* (Ci5) with the ninth volume of this publication having been produced in 2007⁴. Unfortunately, population based cancer registries are absent in most low- and middle-income countries. For example, only five cancer registries from all of Africa were included in Ci5 vol. IX⁴ with these registries covering only about 1% of the population of the continent. Indeed, about 70% of all the data included in Ci5 vol IX⁴ are derived from registries in North America and Western Europe. IARC also produces estimates of cancer incidence and mortality by cancer type, age, and gender for all countries, whether a cancer registry exists or not. These estimates, published and updated periodically as *GloboCan*⁵, can be useful in cancer planning, but it must be recognized that the data upon which they rest is sketchy in many places and non-existent in others.

In their commentary on surveillance and monitoring, the Committee on Cancer Control in Low- and Middle-Income Countries of the Board of Global Health of the US Institute of Medicine of the National Academies recommended the following⁶:

- A. Risk factor surveillance for chronic diseases should be initiated in many countries;
- B. Collection of cause-specific mortality data should be a long-term goal in every country;
- C. Longitudinal studies of chronic risk factors and mortality should be initiated in at least a few additional middle-income countries;
- D. Cancer registries should be developed in conjunction with cancer control activities.

It was recognized by this committee that cancer registries require sustained commitments and trained personnel, both of which are lacking in many countries. Of course, the need for sustained commitments and trained personnel is not limited to cancer registries but

extends across the continuum of cancer control. Human resources have been described as “the most important aspect of health care systems”⁷, yet disparities in the health workforce are enormous⁸. Many low- and middle-income countries have very few physicians and nurses to deliver care, and those that exist are poorly supported in terms of an infrastructure for care delivery. In most low-income countries, emigration of health workers is a significant issue. The term “brain drain” has commonly been used to describe the phenomenon whereby gifted and trained individuals in low- and middle-income countries are lost from those countries *via* emigration⁹. Although “brain drain” is perhaps more poetic, “brain flight” may be more accurate. While it is true that higher income countries offer tangible and intangible incentives for immigration, these are often coupled with strong tangible and intangible disincentives to remain in one's own country. Poor living standards together with political unrest and inadequate infrastructure to support a health care and/or research career all tend to push workers out, while more affluent and stable countries simultaneously pull to meet their own growing needs for healthcare workers.

One of the more prominent features of cancer in low- and middle-income countries is presentation at late stage when curative therapies are less efficacious. In these countries, as many as 80% of cancers are incurable, and patients often die within a year of diagnosis. We know that earlier diagnosis can save lives based on the improvements in cancer outcomes that have been observed in high-income countries where cancers are found when they are more treatable. Late-stage presentation also means more suffering and death due to cancer for a given incidence rate, and more of a sense that cancer equals death. Some have argued that the “myth” that cancer equals death must be dispelled. When cancer is discovered at late stage, it is generally not a myth but a reality. The way to weaken the link between cancer and death is not a public relations campaign aimed at dispelling the “myth” but rather visible improvement in cancer survival over the long haul. In the more immediate term, it must be recognized that many cancer patients in many countries experience unnecessarily painful lives and deaths as a result of inadequate symptom management. “Palliative care” is the integration into cancer care of therapies that address the multiple issues that cause suffering for patients and their families and impact their quality of life¹⁰. An interdisciplinary team is required for the provision of state-of-the-art palliative care. It has been estimated that at least 60% of patients with advanced cancers will experience moderate to severe pain that requires opioid analgesics to control. However, there are many obstacles to effective palliative care services in the countries that need it most. These obstacles include a shortage (or absence) of healthcare workers with training and experience in palliative care delivery as well as barriers to the delivery of pain med-

ications that are a cornerstone to pain management within palliative care.

In conclusion, the ability to respond to the population's need for improvement in cancer control outcomes is contingent upon:

1. Is the size of the problem known now and into the foreseeable future? Is there a registry that can collect accurate, complete (as determined by context) and timely information about incidence, mortality and other measures of cancer burden, upon which rational planning can take place? These considerations are discussed in sections 2, 3, 5, 9, and 10 from perspectives including information acquisition, management and analysis, and from collaborations between countries at varying levels of capability to host population registries.
2. Is there a plan (population-based) to align capacity to meet needs and to ensure access to interventions and services from prevention to palliation/end-of-life care, in a manner appropriate to the context of the nation (sections 4, 6, and 7)?
3. Is there a means to monitor and survey plans on a continuing basis, to measure the performance of plans and outcomes, to establish impact and to report outcomes, such that priorities and resource allocation (including human resources) are based on evidence of benefit and the sustainability of the plan is based on performance and outcomes (sections 8, 12, 13, and 14)?
4. Are disparities of outcome within the population measured? Is the mitigation of disparities integral to the purpose of the population-based plan (sections 11 and 15)?

These reports illustrate the synergy that can result through communication, cooperation, collaboration and coordination within and across plans, people and populations.

2. Cancer Atlas revisited: role of information technology in data capture

Ambakumar Nandakumar

Under a project entitled ‘Development of an Atlas of Cancer in India’, a cost-effective plan using advances in modern electronic information technology was conceived to collate and process relevant data on cancer. The objectives were to obtain an overview of cancer patterns and estimate cancer incidence wherever feasible. The Internet, through a web-site (www.canceratlasindia.org), was identified as the primary communication medium¹¹.

Some of the cancer patterns that arose were expected, but several new ones emerged. The high occurrence of cancer (all anatomical sites) in general and certain can-

cers, such as stomach and lung in the North Eastern states, were a revelation.

The data from the Second Report of the population based cancer registries of the North East for the years 2005 and 2006 revealed that for all anatomical sites of cancer, Mizoram state had an Age Adjusted Incidence (AAIR) of 191.5/100,000 in males and 155.0/100,000 in females¹². The main anatomical site of cancer that contributed to the high incidence in males in Mizoram state was stomach cancer, which accounted for almost a quarter (23.6%) of all cancers in that sex.

The initial report on the cancer atlas was thus corroborated by the results of the above report of the population based cancer registries that were commenced subsequently in the same areas. The concept of using a web-based design and approach with on-line transmission of cancer data has worked, which is a major advance for using Information Technology in Medicine and Measuring Disease Burden and Health Informatics.

3. The Middle East Cancer Consortium: an example of regional cooperation in cancer registry and palliative care activities

Joe B Harford

The ancient Egyptians recognized over 200 separate illnesses including “swellings” known as *henhenet* and *aat* thought to denote tumors. *Henhenet* were treated with dressings (chemotherapy) whereas *aat* were treated with excision (oncological surgery). The Ebers Papyrus (~1550 BC) stated “to relieve any painful part..., the body is anointed and exposed to the sun” (radiation therapy, perhaps using chemical radio sensitizers). Ancient Hebrew literature also makes mention of “tumors” (e.g., Deut. 28:27; I Sam. 5-6). Despite this recognition and treatment of cancers in the ancient Middle East, our current knowledge of cancer incidence there has been limited due to a shortage of population-based cancer registries in the region. In 1996, a partnership known as the Middle East Cancer Consortium (MECC) was formed, and MECC took on cancer registration as its first cooperative regional activity. Current MECC membership consists of Cyprus, Egypt, Israel, Jordan, Palestinian Authority, and Turkey. MECC, in conjunction with the relevant ministries of health and with support from the US National Cancer Institute (NCI), has sought to establish population-based cancer registries where these were lacking and to enhance existing registries *via* training of staff and quality control exercises. MECC-supported population-based registries are intended to cover the entire populations of the government-controlled portion of Cyprus, as well as all of Israel, Jordan, West Bank and Gaza. In the case of Egypt and Turkey, each of which has a population of >70 million, their MECC-supported registries cover districts around the cities of Tanta and Izmir, respectively. The MECC reg-

istries have cooperatively developed manuals of standards and practices to make data more comparable. An NCI monograph has been published in which data from four of the MECC-supported registries were compared with U.S. data from SEER¹³. This monograph contains chapters on various cancer sites with suggestions for additional research based on the region's cancer incidence data.

As an example of MECC registry data, consider breast cancer. Breast cancer is the most common cancer in women in all jurisdictions covered by the NCI MECC Monograph, although the incidence rates vary significantly among the populations. Figure 1 displays the incidence rates for breast cancer by age within those jurisdictions whose data were included in the Monograph. Rates are higher in US women and Israeli Jews and lower in women from Egypt and Jordan as well as in non-Jews (Arabs) within the Israeli registry. Cypriot breast cancer rates are intermediate. It is commonly believed that breast cancer occurs in younger women in Arab populations (and in low- and middle-income countries generally) *i.e.* the average age of diagnosis is younger. However, average age may not be a very meaningful way to consider the rates of breast cancer in these populations, because the perception that many younger women develop breast cancer is largely due to an overall lower average age for the population of women in low- and middle-income countries. Although the average age of breast cancer is indeed lower, so would be the average age for any number of things given an age pyra-

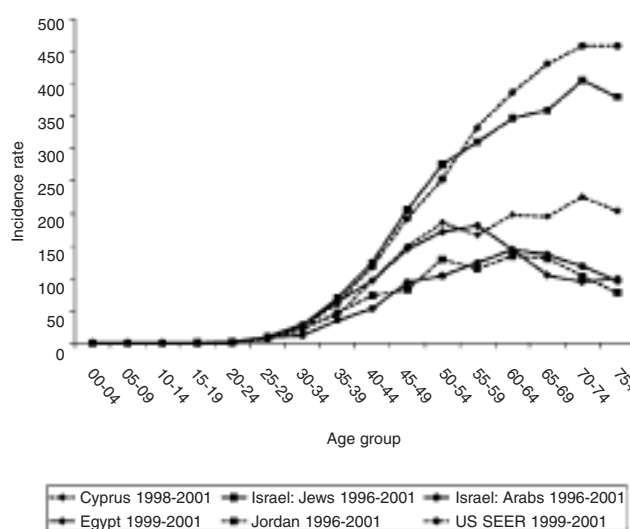


Figure 1 - Age-specific incidence rates of breast cancer among females in Cyprus, Israel, Egypt, Jordan and US SEER, 1996-2001.

Figure derived from: Freedman LS, Edwards BK, Ries LAG, Young JL (eds): *Cancer Incidence in Four Member Countries (Cyprus, Egypt, Israel, and Jordan) of the Middle East Cancer Consortium (MECC) Compared with US SEER*. National Cancer Institute, NIH Pub. No. 06-5873, Bethesda, USA.

mid skewed markedly toward younger ages overall. In fact, there is no age where the incidence rate of breast cancer in any of the MECC Arab populations is higher than that of the corresponding age group in the U.S. data (Figure 1). The incidence rates in the Arab populations are closer to those of the US at younger ages, probably reflecting a birth-cohort effect whereby the risk of breast cancer in younger women is higher than that of their mothers and grandmothers at comparable ages (but not higher than their US counterparts). This birth cohort effect has been seen in other populations examined over time including the US, and seems to accompany development, possibly reflecting changes over time in reproductive patterns (fewer children, later children, etc.). These observations and interpretations regarding breast cancer in the region warrant further research. The descriptive epidemiology of the NCI MECC Monograph raises analogous questions needing more research about other cancer sites.

Arguably, the most significant feature of cancer in most of the MECC jurisdictions is that of diagnoses at late stage when curative therapy is less efficacious. Therefore, the MECC members have taken on palliative care as their second cooperative regional project. A baseline situation analysis on palliative care services was conducted and its results published as an NCI monograph¹⁴. In most of the MECC jurisdictions, palliative care services are lacking or are severely inadequate. MECC, with NCI support, has sought to address this inadequacy *via* capacity-building training activities that include group workshops on specific relevant topics, workshops aimed at healthcare workers in a specific jurisdiction, and individual training activities.

In conclusion, MECC has demonstrated that cooperation, aimed at understanding and ultimately reducing the burden of cancer, can bear fruit despite a history of conflict among and between the participants. Thus, MECC serves as an example not only of regional cooperation but also of “medical diplomacy”. The financial support of NCI, even if modest, is considered to have been critical to the success of the MECC endeavor. In addition to its provision of financial support, NCI has also facilitated training and the bringing of technical expertise to assist both the regional registry project and the regional palliative care project of MECC. The NCI's involvement with MECC is mediated by its Office of International Affairs (<http://oia.cancer.gov/>). Over time, the value of population-based cancer registries has come to be more appreciated within the jurisdictions of MECC *e.g.* the governments of both Egypt and Turkey have committed to expanding their cancer registry to create a national network of population-based registries in the two countries built in part upon their MECC experience. Data from a second Turkish registry along with the data from the MECC-supported registry at Izmir were included in Volume IX of Ci5⁴.

4. The Cancer Control PLANET (Plan, Link, Act, Network with Evidence-based Tools) online web portal – a widely used tool in North America for effective program planning, implementation, and evaluation

Brenda K Edwards, Cynthia A Vinson, David G Stinchcomb

The online web portal, Cancer Control PLANET (Plan, Link, Act, Network with Evidence-based Tools), designed by NCI and sponsored by a consortium of public-private partner agencies, has been an effective toolkit for cancer control planning, program implementation, and evaluation systems in the US. Released in 2003 with continuous updates to data sources, user interface, and outputs, the Cancer Control PLANET initiative is structured around a five-step process of comprehensive cancer control planning using inputs from publicly verified data sources, independently conducted evidence reviews for targeted interventions, and usability-tested interactive mapping and data visualization displays. The five steps include the following:

1. Assess the cancer and/or risk factor burden within a given state using State Cancer Profiles, which includes cancer registry data from the NCI Surveillance, Epidemiology and End Results (NCI-SEER) Program and the Center of Disease Control and Prevention National Program of Cancer Registries (CDC-NPCR). U.S. state and county incidence (at least 75% coverage) and mortality (100% coverage) can be generated utilizing comparison tables and charts.
2. Identify potential state, national, tribal and territorial partners for cancer control or research activities, from lists containing detailed contact information. This provides the opportunity to find potential partners working with community-based programs and fill gaps, where they exist, in program service delivery.
3. Read the latest evidence reviews on the effectiveness of different approaches to cancer prevention, control and early detection. Scientific publications describe various intervention strategies, such as clinical guidelines for treating tobacco use and dependence and the use of psycho-educational interventions for pain control in adult cancer patients. Included are the federally sponsored *Guide to Community Preventive Services* and *Guide to Clinical Preventive Services*.
4. Select methods and materials from more than 90 Research-tested Intervention Programs and products (RTIPS) covering 9 topic areas (diet, physical activity, cancer screening, informed decision making, etc.) to address identified objectives. Available products address community-based intervention programs, physician-based curriculums, health awareness programs and many other strategies. Users are able to preview and download the majority of the materials free of charge.
5. Use developed cancer control planning tools to adapt each intervention component for other community

or clinical settings. Examples of cancer control programs and evaluations are available for building and evaluating a comprehensive cancer control plan.

Web metrics and survey results of Cancer Control PLANET professional users indicate that all five steps were not used in sequence, at the same frequency, or considered of similar value. State Cancer Profiles (Step 1) and the Guide to Community Preventive Services (Step 3), were frequented the most. The most common topic areas were Diet/Nutrition and Breast Cancer Screening. An association was found between the increased usage of RTIPs and the amount of NCI trainings and exhibits for Cancer Control PLANET.

Cancer Control PLANET offers several effective ways to expand cancer control efforts globally and has recently partnered with the Canadian Partnership Against Cancer to develop a Canadian version of the site.

5. Web platform for population based registries

Altino Ribeiro Leitao, Zina Pinheiro, Paulo Pereira Camanho, Eduardo Jose Vichi

Through the identification of health problems, disease surveillance programs are able to establish health policy. One of the main tools in such programs is access to incidence and mortality data^{15,16}. In order to closely monitor the quality of Brazilian incidence data the Brazilian National Cancer Institute (INCA) and the Foundation of Cancer (FdoC) have begun development of the Population-based Registry Web System (Basepop Web).

Once the new on-line system is adopted, these registries will benefit from the following features:

- access to standard centrally maintained tables such as ICD, TNM and location (region, state and cities);
- real time access to databases by the central administration facilitating consistency checks – leveled quality assurance;
- import data automatically from various sources – National Obituary Database (SIM), Hospital-based Cancer Registries (RHC), National cancer screening programs and cancer cases from clinics and health units with information systems;
- automatically export information to IARC for publication;
- business Intelligence architecture for final reports and decision making tools.

Another benefit of the new Population-based system is the case matching process that will allow cases from various sources to be compared and merged, creating one complete registry.

The Population-based Cancer Registry Web System is being developed using free development tools such as

Java platform (JSE 5) and PostgreSQL database. All transactions have security certificates ensuring secure communication of patient information. This web-based system is easily portable to other countries searching for solutions for quality assurance in their registries.

6. National cancer control programs capacity assessment: a joint WHO-IAEA initiative

Cecilia Sepulveda, Massoud Samiei

Currently, WHO is strengthening its efforts to assist countries in building and reinforcing capacity for planning and implementing effective national cancer control programs (NCCP). Within this context, WHO is developing an NCCP capacity assessment tool as part of a broader capacity surveillance system for non-communicable diseases.

In order to carry out a rapid, simple and inexpensive capacity assessment, an online NCCP core self-assessment tool has been developed. This tool is considered an initial step by both WHO and IAEA towards the implementation of the recently agreed Joint Program on Cancer Control. A more detailed assessment tool that allows in depth analysis of all cancer control components, including radiotherapy, will be employed based on the methodology used by IAEA/PACT (imPACT Reviews) for its country assessment missions.

The main objective of the NCCP core self-assessment tool is to identify gaps and strengths, monitor progress, and support advocacy and capacity building efforts of cancer control plans and programs at country, regional and global levels. Another important objective is to facilitate the integration of radiotherapy within a broader cancer control effort to maximize outcomes. Thus, the NCCP capacity assessment is conceived as a collaborative effort with shared responsibilities and reciprocal benefits for countries, WHO and IAEA.

The core self-assessment tool is based on the WHO evaluation framework described in a manual on how to develop effective programs¹⁷. It is designed to be completed by a multi-sectoral and multidisciplinary team of 5 to 7 members who belong to the national cancer control committee at the Ministry of Health. The survey is at present undergoing field-testing in approximately thirty selected countries. Once the tool has been finalized, countries will be invited to use this tool as part of their NCCP monitoring and evaluation activities.

7. Estimating resource requirements for meeting human resources for health

Marty Makinen, Maria Stella de Sabata, Mubashar Sheikh

Background The shortage of health workers worldwide was estimated in 2006 at 4.2 million, including over 1 million in Sub-Saharan Africa¹⁸. The Global

Health Workforce Alliance (GHWa) was created the same year as the global focal point on the health workforce crisis (<http://www.who.int/workforcealliance>).

Methods GHWa establishes mission-oriented, time-bound Task Forces/Working Groups (TF/WG) to address specific challenges in priority areas. Among the objectives of the Financing Task Force was to develop and test a tool for country-level planners and decision-makers to estimate and project the costs of health workforce plans.

Results The Resource Requirements Tool (RRT) is a hands-on, Excel-based tool, ready for country use, that can:

- estimate and project the resources required for meeting their Human Resources for Health (HRH) plans;
- analyze the plans' affordability;
- simulate "what if" scenarios;
- facilitate the monitoring of scale-up plans;
- contribute to the development of the cost and financing component of Human Resource Management Information Systems.

The target audience of the RRT includes Ministries of health, education and finance, parliaments, and development partners. As of May 2009 the RRT was used by Ministries of Health in Liberia, Mozambique, Uganda, Ethiopia, Ghana and the Philippines.

The RRT includes three interlocking modules on:

- comprehensive costs of employment in the public sector, while accounting for HRH employed in the private sector;
- costs of pre-service training to meet HRH plans, while accounting for HRH demand and production in the private sector;
- affordability of HRH employment and pre-service training.

Conclusion The issue of the availability of qualified personnel is well-known to the cancer control community. GHWa hopes that the Resource Requirements Tool can help countries estimate and project the resources required for workforce scale-up as they plan for viable and affordable comprehensive cancer control.

8. Monitoring the progress of national cancer control in the Netherlands

Marjan Gort, Sabine Siesling, Renée Otter

In the Netherlands, the NCCP 2005-2010 has been developed to manage and improve the quality of cancer control and care. In this program, goals were set for all aspects of cancer control, from primary prevention and screening, care and cure to end of life care, education and research. Indicators were defined to measure progress and a monitoring instrument was developed to appraise

the quality of cancer control and assess the achievements of the NCCP goals. The instrument therefore supports priorities in policy, quality improvements and (inter)national benchmarking, as it aligns with other indicator sets, e.g. Eurochip and the Ontario Cancer System Quality Index. The monitoring reports include national data on a selected set of indicators. This set includes various risk factors for cancer for primary prevention, secondary prevention indicators from the population-based breast and cervical cancer screening programs, and indicators for cancer care, including incidence, stage at diagnosis, compliance with guidelines, time from diagnosis to treatment, mortality, and 5 year relative survival.

The Monitor 2008 shows that, on a national basis, survival of cancer patients increased during the last decade due to earlier detection (breast and prostate cancer) and improved treatment (e.g., colorectal and lymph node cancer) (www.npknet.nl/monitor). However, for lung cancer these improvements are lagging behind, as curative treatment is often not achievable. Only 13% of lung cancer patients are still alive 5 years after diagnosis. Consequently, in the battle against cancer, prevention of lung cancer deserves top priority, and smoking cessation is the most important preventive action.

The NCCP Monitor provides information to the Steering Group and other policymakers to renew priorities in policy against cancer. It reinforces coordinated improvement activities on a national, regional and local level on different aspects of cancer control in the Netherlands. In the coming years, the monitoring instrument will be expanded to include other indicators.

9. International efforts in planning and monitoring population based systems to track cancer communication constructs

Lila J Rutten, Terisa Davis, Guillermo Tortolero Luna, Richard P Moser, Kia L Davis, Ellen Beckjord, Bradford Hesse

Background The Health Information National Trends Survey (HINTS)¹⁹ sponsored by the US NCI provides surveillance of the nation's investment in cancer communication and examines the effects of a changing communication environment on cancer-related knowledge, attitudes and behavior. NCI, in a collaborative effort with the Cancer Control and Population Sciences Program of the University of Puerto Rico Comprehensive Cancer Center and the Department of Health in Puerto Rico, Puerto Rico Behavioral Risk Factors Surveillance System, implemented HINTS in Puerto Rico in 2008.

Objective The primary aims of this presentation are to describe an international collaboration to increase our knowledge of the information needs, cancer-related knowledge, and behavior of Hispanic populations, and assess the feasibility of sharing survey resources in the context of international collaboration.

Results Data collection for HINTS Puerto Rico was initiated in April 2009 and will be complete ($n = 600$) in June 2009. Initial planning is underway to connect with key cancer control and communication planners in Puerto Rico to discern optimal ways to utilize and disseminate this data. Results of these efforts will be shared as well as a step-by-step overview of how HINTS was implemented in a new population and lessons learned from this expansion.

Conclusions This collaboration will inform future international partnerships around a shared mission of planning and monitoring population based systems to track cancer communication constructs and contribute to cancer control efforts in Puerto Rico.

10. Using cyberinfrastructure to plan and monitor population based systems, activate communities, and enable infrastructure partnerships

Richard P Moser, Ellen Beckjord, Kia L Davis, Lila J Rutten, Bradford Hesse

Background Developing countries are disproportionately affected by cancer incidence and mortality, and have limited resources to plan and monitor population based systems for cancer control. There is a need to identify tools that facilitate collaboration among international researchers, especially those from low-resource countries²⁰.

Objective This talk will describe how the US NCI is using cyber-infrastructure to develop a platform to enable a virtual community of researchers to access, share, and analyze data from different population-based systems. We will describe and demonstrate the NCI's Grid Enabled Measures (GEM) database, an interoperable, dynamic, web-based tool connected to a grid infrastructure. The primary aim of this presentation is to raise awareness of cyber-infrastructure applications among a global community of cancer control researchers, using GEM as an example.

Results Using a wiki-model to create an architecture that facilitates global participation and enhanced collaboration, GEM will enable the use of standardized survey items, thereby creating harmonized data that can be shared by a virtual community of cancer control researchers. It will also be shown that GEM can facilitate translation of survey items into different languages, creating a universal translation community. The resources and data generated by the GEM community could be leveraged at a local level for community activation around cancer control.

Conclusions The success of cyber-infrastructure initiatives is dependent upon user participation. Cyber-infrastructure and tools such as GEM allow international researchers, especially those from low-resource countries, to easily participate in a larger community of can-

cer control research to promote and enhance community-based cancer control programs.

11. Using population based data surveillance systems to eliminate disparities in cancer control

Kia L Davis, Rebecca Anhang Price, Jill Koshiol, Jasmin Tiro

Background Over 90% of cervical cancer cases are preventable, yet it remains a leading cause of cancer death among women worldwide. The Human Papilloma Virus (HPV) vaccine has the potential to significantly reduce this cancer burden. The vaccine protects against two strains of HPV that cause approximately 70% of cervical cancers. Since its approval in the US, media attention around HPV and cervical cancer has heightened. Little is known about how this attention may impact knowledge and awareness in populations most likely to benefit from the vaccine, particularly women who have traditionally low rates of cervical cancer screening²¹.

Objective This talk demonstrates use of surveillance data from the HINTS²² to identify HPV and cervical cancer knowledge gaps among populations in the US.

Methods Data were from respondents of HINTS 2005 ($n = 3,072$) and HINTS 2007 ($n = 1,903$).

Results After vaccine approval, there were significant increases in the proportion of women aged 18-75 who had heard of HPV (82.01%, +41.96, $P < .001$), knew that it caused cervical cancer (68.90%, +21.23, $P < .001$), and knew that it often resolves without treatment (6.38%, +2.61, $P < .05$). Knowledge that HPV is a sexually transmitted infection remained virtually unchanged (61.77%). Older women, ethnic minorities, and women who mistrust at least one health information source were significantly less likely to have heard of HPV and to know that HPV causes cervical cancer compared to younger women, Whites, and women who trust all health information sources.

Conclusions The collection of HINTS data allows for identification of groups in greatest need of education regarding new healthcare technologies, such as the HPV vaccine, which have the potential to reduce the burden of cancer particularly in vulnerable populations.

12. Evaluation, monitoring, and stepwise improvement of cervical cancer screening

Dik Habbema, Marjolein van Ballegooijen

Cervical cancer screening has suffered from the lack of randomized controlled trials. As a consequence, all over the world millions of smears have been taken sub-optimally or have even been harmful because of too frequent screening. In the Netherlands, screening for early detection of cervical cancer and its precursors was ini-

tially poorly designed. In particular, the age range of women invited (35-53 years) to participate was too narrow and no attempts were made to suppress the frequent opportunistic screening. During the subsequent years and even decades, a stepwise improvement of the screening program was realized²³. Based on a cost-effectiveness evaluation using the MISCAN model, it was decided that all women aged 30 to 60 years should be invited at 5 years intervals. Opportunistic screening was discouraged by stopping its reimbursement. The number of positive smears requiring follow-up was reduced from 10% to 2%, based on epidemiological studies linking initial and subsequent screening results and the cancer registry. Follow-up of positive smears was also improved. Presently, the cervical cancer screening program in the Netherlands ranks among the best worldwide. In addition, new developments in screening have been studied, including automatic smear evaluation, thin layer techniques, HPV screening, HPV tests for triage and more recently HPV-vaccination.

Elements that enabled improvements in the Netherlands screening program included registration of invitations, smear results, follow-up, and final histological diagnosis and monitoring of cancer incidence and mortality. The national evaluation team, supported by a scientific evaluation group, was also pivotal. Cost-effectiveness of the improvements and implications for low- and middle-income countries will be discussed.

13. Breast cancer stage at diagnosis and survival in Europe and in Cuba

Claudia Allemani, Yaima Galán, Leticia Fernández, Milena Sant and the EUROCARE-3 high resolution breast cancer Working Group

Background The first CONCORD analysis provided an overall comparison between survival in Europe and Cuba²⁴. The aim of this study is to analyze the stage distribution and stage-specific breast cancer survival in the two areas.

Material and methods We analyzed 13,052 cases from the EUROCARE-3 High Resolution (HR) dataset²⁵, originating from 11 European countries, and 6,037 cases from the Cuban National Cancer Registry, diagnosed between 1996-1998. Stage at diagnosis was grouped into six categories: *in situ*, early (T1N0M0), large, node-negative (T2-3N0M0), node-positive (T1-3N + M0), locally advanced (T4N +/- M0), metastatic (M1) tumors, and stage not specified. Five-year observed survival was estimated using the Kaplan-Meier method.

Results *In situ*, early, node-positive, locally advanced and metastatic tumors were more frequent in the European data than in Cuba (1.6% *vs* 0.3%; 29.3% *vs* 11.3%; 31.7% *vs* 19.3%; 8.3% *vs* 5.4%; 5.9% *vs* 2.2%, respectively) while the opposite was found for large, node-negative tumors (13.7% *vs* 20.8%). Five-year observed sur-

vival for early, large node-negative and node-positive tumors was very similar for European and Cuban women (92% *vs* 92%; 85% *vs* 82%; 75% *vs* 77%, respectively) whereas inconsistent results were found for advanced stage tumors in Cuba. In addition, in Cuba, the proportion of unstaged cases was very high (40.7% *vs* 9.5% in the European data).

Conclusions This preliminary analysis shows that the prognosis of Cuban women with breast cancer was similar to that for European women for early and localized tumors. Definitive results could not be obtained for advanced and locally advanced stage tumors. This may be explained by the high proportion of unstaged tumors in Cuba, indicating the need for high-resolution studies to collect stage information from clinical charts and to improve the data quality of the Cuban Cancer Registry.

14. Development of a national system performance reporting system

Heather Bryant, Mary Spayne

Canada enjoys publicly funded health care, yet the organization of health care services occurs on a provincial/territorial basis. Canada has a strong registry system, and some national collection of risk factor data, but there has not been a national approach to reporting on needs and performance across the cancer control system. A priority of the Canadian Partnership Against Cancer, the organization funded by the Canadian government in 2007 to implement a national cancer control strategy, is to develop, and to report on, a deeper understanding of the performance of the cancer control system. An indicators sub-group held a national workshop in February, 2008, at which cancer control professionals narrowed the several hundred indicators identified in an in-depth literature review to several dozen. Following this, a committee comprised of senior cancer control professionals and administrators reduced the list further, based on specific prioritization criteria. A national survey of the availability of data was then undertaken, and a list of 17 indicators was identified for the first report. These cover population incidence and mortality data, survival analyses, risk factor prevalence, wait times for therapy, system infrastructure, and progress in such areas as availability of cancer staging information. Workshops were held with the potential recipients of the reports to receive feedback on the reporting style and content, and results will be presented to provincial cancer agencies and policymakers in regional workshops later in June. The report will show regional variations in quality of data, and has also identified gaps in availability of data in some parts of the cancer control continuum. In addition, some work has been done to examine the indicators according to social determinants data (income, education, rural/urban residence), with interesting results in the relationship of several in-

dicators to income. The workshops will also identify potential areas for future indicator development.

15. Understanding cancer treatment and outcomes in the community: the Cancer Care Outcomes Research and Surveillance Consortium (CanCORS)

Dee W West, John Z Ayanian, Elizabeth A Chrischilles, Robert H Fletcher, Mona N Fouad, David P Harrington, Katherine L Kahn, Nancy Keating, Catarina Kiefe, Joe Lipscomb, Jennifer L Malin, Arnold L Potosky, Dawn T Provenzale, Robert S Sandler, Michelle van Ryn, Robert B Wallace, Jane C Weeks

Cancer treatment and outcomes are not optimal for many cancer patients in the US and studies are needed to complement information from randomized clinical trials with information from patients living in communities throughout the US. The Cancer Care Outcomes Research and Surveillance Consortium (CanCORS) was organized in 2001 to identify clinically important differences in cancer treatment and outcomes for lung and colorectal cancer patients according to characteristics, such as gender, race/ethnicity, and age²⁶. The Consortium includes investigators from five cancer research institutions, a network of managed care organizations, and the US Veteran's Administration. Over 5,000 lung and 5,000 colorectal cancer patients were recruited and patient data were obtained from baseline and one-year post diagnosis interviews. In addition, data were obtained from caregivers, physicians, medical records, and linkage with Medicare records. This collaboration represents a new model to study cancer care: a large distributed, multidisciplinary team of investigators collecting shared data. This model allows questions to be answered, such as why racial, economic, and geographic differences exist in treatment and outcomes, why older patients receive less aggressive treatment, why participation in clinical trials is so low, how decisions regarding treatment are made, what is the impact of cancer on caregivers, and what is the effectiveness of treatments for patients who are generally excluded from clinical trials? This presentation will describe the CanCORS model and present data addressing many of the above questions.

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